

Social Casework for Patients with Hansen's Disease

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HANSEN'S DISEASE, also known as leprosy, is an ancient, communicable disease that is still important socially, economically, and medically in many parts of the world. In this country it is far less prevalent than in certain other countries, since those known to have the disease in the United States probably do not exceed 2,500. By contrast, overpopulated and underdeveloped India has about 1.5 million cases. This chronic, systemic disease is caused by the bacillus *Mycobacterium leprae*. It is described as being "mildly communicable" and is probably the least communicable of the bacterial diseases. Hansen's disease is not inherited, but a familial susceptibility factor is believed to exist. When exposed, some individuals are more prone to develop the illness than others. Since the hospital at Carville, La., was founded 69 years ago, no known cases have been contracted by the staff members. The method of transmission seems to be from an infected person to a well individual by prolonged and intimate skin-to-skin contact.

Every illness has its social aspects, and it is important to look at the way in which society views a particular illness. Lack of knowledge and adverse attitudes of others can thwart treatment efforts and also have deleterious psychological and sociological effects on the sick person and his family.

Throughout the ages the plight of the person with Hansen's disease has indeed been deplor-

able. Even today, in some countries, the "beggar's lot" is the only niche relegated to him. Leprosy continues to be greatly feared, and the social stigma usually associated with it is almost universal. The fear and prejudice that surround it apparently arose because of the mutilation and disfigurement sometimes seen in those with advanced disease. Although some other diseases mutilate and ravish the human body, few have engendered the deep feelings attached to leprosy.

Until two decades ago no effective treatment was known, and this in itself was fear provoking. Today there is hope for the person diagnosed as having Hansen's disease, since effective treatment agents are available and more are in the process of being developed. Cases are being recognized earlier, and in many instances this reduces the length of hospitalization necessary to achieve arrest of the disease. Prior to the discovery of the sulfones in the early 1940's, patients remained in the hospital for many years—some for the remainder of their lives. At present the average length of stay for the newly diagnosed patient is less than 5 years. Much depends on individual response to treatment, and some patients leave the hospital in approximately 1 year.

The dissemination of factual information through various media has promoted public awareness and more rational understanding of Hansen's disease, and improvement in public attitudes toward the person with leprosy has been noted. In many communities knowledge and understanding have replaced fear and prejudice. A willingness to accept patients back home after treatment for Hansen's disease is being observed more frequently; previously

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they often met with much adverse feeling. As with tuberculosis, mental disorders, epilepsy, and other illnesses, the social stigma of the condition can be the most difficult factor for the patient. It may concern him more than the disease itself.

The Public Health Service Hospital (National Leprosarium) at Carville cares for about 310 persons with Hansen's disease. The hospital buildings are situated on a 337-acre tract of land on the east bank of the Mississippi River, 75 miles northwest of New Orleans and 25 miles south of Baton Rouge. The State of Louisiana transferred control of the hospital to the Federal Government in 1921, and since that time it has become world famous for its contributions in research and in the treatment and rehabilitation of the leprosy patient.

A social service department with a professional worker was established at Carville in July 1950. The myriad personal and social problems the social worker encounters are similar to those of patients in other chronic disease hospitals.

Carville's Objectives

Among the hospital's objectives, as formulated by Dr. Edgar B. Johnwick, medical officer in charge, are:

1. To give medical and surgical care to leprosy patients and to record, evaluate, and report such experiences in order to improve the management of cases.

2. To collect and analyze epidemiologic information on all admitted cases so that more effective public health measures may be taken to control leprosy in the United States and elsewhere and to maintain liaison with State health departments and bureaus and divisions of the Federal Government concerned with the control of leprosy.

3. To conduct research in leprosy and its control and to cooperate with government and private agencies conducting studies that promise to yield information which will help control leprosy.

4. To disseminate objective information on leprosy, its public health aspects, and control measures to medical, paramedical, and lay groups in order to balance extreme opinions

concerning leprosy and to help put in effect the measures needed to bring the disease under control.

5. To institute and maintain an active rehabilitation program using all existing resources and exploring, developing, and acquiring new resources to motivate and prepare the patient for return to his former community as an acceptable and contributing member of society.

The Patients

Patients are drawn from all parts of the country and various ethnic groups. They have diverse cultural backgrounds. Many are bilingual, but some speak only the language of their cultural origin, which can complicate communication with them. Differences in dietary habits and attitudes toward disease, illness, and medical care may also be factors in their adjustment to the treatment regimen. The educational level of the patients tends to be somewhat below the U.S. average.

At Carville, the age range of the patients is from 7 to 93 years, with the average age about 40. Approximately 20 patients are under 21. The male patients outnumber the female 2 to 1; this ratio is maintained in other such hospitals throughout the world. There are 25 married couples, who met after becoming patients at the hospital.

Each patient has a private room that he can decorate to his taste. Certain pets are permitted, and many birds, tropical fish, a few dogs, and cats may be seen. When both husband and wife are under treatment, the couple is provided an attractive private, furnished house that is landscaped and air conditioned. Many patients keep their automobiles on the hospital premises.

Special arrangements are made for the young patient to live in the home with a married patient couple. The children receive special attention, affection, and guidance in what corresponds to a foster home within the hospital setting. The married couple is selected carefully with the help of the social worker and other staff members. This "made family" is voluntary. Continual guidance is given by the social worker in matters involving the emotional growth of the child.

Patient Activities

A 60-bed infirmary is fully equipped to provide complete care of patients recovering from surgery, those undergoing diagnostic workups, and those having "leprous reactions" or flare-ups of their disease. Other patients require physical therapy, intravenous sulfone injections, and extensive medical care. The majority of patients are ambulatory and receive oral medications at mealtime. They have considerable time on their hands that must be filled in some way.

Constructive use of hospital time is of prime import. At Carville, activity is purposeful and has a definite goal. A program is planned in accordance with the patient's individual needs. If he had to leave school to go to work, he may wish to continue his education. Patients are encouraged to take advantage of Carville's educational program, accredited through high school. Work may seem to be the primary need, which can be met by part-time, paid employment in the hospital. In some cases a combination of education and work is indicated.

There are also opportunities to learn skills for certain vocations that the patient can follow when he is discharged. Trainee positions include hospital nursing assistants, occupational and physical therapy aides, janitorial or custodial workers, gardening and grounds maintenance workers, woodworkers, and clerks. Several patients are employed part time at the hospital as skilled secretaries, and others have continued in this occupation, learned in the hospital, following discharge. A patient may also learn to operate a linotype machine, press, or other equipment in the print shop.

Patient organizations include a Lions Club, garden club, art club, religious and music groups, and others serving special interests. An American Legion Post is composed of the 35 veterans among the patients who served in one of the last three wars. The Patients' Federation, to which all patients belong, operates a well-stocked store with grocery and meat department, canteen or food service section, and a post office. A patient group operates a print shop and publishes the *Star*, a bimonthly periodical devoted primarily to promoting public understanding of Hansen's disease, the hospital program, and patient activities. A softball

team competes in the local league, and golf tournaments, an annual fair, Mardi Gras ball, special dances, and entertainment are all a part of the professionally supervised recreational program. There are Catholic and Protestant churches at Carville with full-time chaplains.

Social activities provide an essential link between the patient and the community outside the hospital. The association with veterans groups, visiting softball teams and golfers, and other guests gives the patients the feeling that they are still in the stream of life. The patient with Hansen's disease has a constant need to be reassured that he is not rejected by society. A feeling of isolation from the human family slows his recovery and retards efforts at rehabilitation.

Visits to the hospital by the family and passes for patients to go home on leave break the monotony of hospital routine. These vacations can be therapeutic and actually a part of treatment. Eligible patients are encouraged to take 30-day leaves twice a year.

Blind patients with long-standing disease present special problems. Along with absence of vision is usually lack of sensation, particularly of extremities. This is caused by damage to the sensory nerves, which precludes Braille reading and makes getting about quite difficult for some of them. These patients are in the minority, since the eye damage was inflicted before the advent of modern medications. Talking books, occupational therapy, music, social gatherings, and volunteer letter writers all help them to adjust to their situation. Some blind patients are leaders in the patient community.

Pre-Admission Planning

The hospital not only serves the needs of the patient but also those of the community. Since Hansen's disease is considered to be communicable, society asks protection from possible infection. If there is a need for isolation, this is often a difficult, added burden for the sick person.

All patients and their families need the help of a social worker in pre-admission planning. This is usually done by a worker in the patient's home community with direction or advice by

telephone or letter provided by the hospital social worker. Regardless of how enlightened about leprosy a community may be, some unfavorable reaction may be precipitated by ill-considered publicity. The patient need not expect this to happen, as in most instances it will not; however, the social worker can help to prepare him to cope with such an event. Occasionally, the caseworker must use an interpreter to work with some families, but this practice leaves much to be desired.

The time of diagnosis is usually an extremely trying period filled with anxiety and emotion. If hospitalization is indicated, it means leaving the familiar surroundings of home and, for most patients, traveling to another State for an undetermined period of treatment in an institutional setting. The patient's family life is disrupted, and his feelings about being set apart because of an illness can be most disheartening. Impulsive reactions may be flight, withdrawal, or aggressive hostility. Dislocation from a happy environment can cause emotional illness, and this compounds the basic medical condition. Patients show disbelief of their diagnosis and shock that this could have happened to them. Sometimes their feelings are covered by a façade that can usually be removed.

Tact and casework skill are required to prepare a family for the temporary loss of a breadwinner, mother, or child. Major tasks at this stage are to insure a source of income for the family if the ill person is the provider, to prepare other family members to assume responsibilities the ill member can no longer bear, and to facilitate separation as much as possible. Often the first question asked by the person with Hansen's disease, when told he should enter the hospital, is, "What happens to my family now?" Monetary benefits that might be forthcoming should be brought to his attention and applied for if he wishes. Such benefits may include social security disability payments, veterans disability pension, and trade union or similar benefits under private insurance programs. Family deprivation can cause severe guilt feelings in the sick person who is usually adequately provided for in the hospital.

The social worker coordinates his efforts with the community and State agencies that can

provide financial and other assistance to the family. State and county health departments and the family physician assist in the followup of family contacts who have been exposed to the patient's disease. The State department of welfare may certify a grant, or the employment agency may assist in finding work for a spouse or other member of the family who may not have been employed. The American Red Cross, the churches, and the Salvation Army are often called on to help, depending on the family's particular needs. Usually many helping resources can be tapped.

The anxieties of separation are manifold and are observed in all family members in different degrees. Some need more help than others because individuals vary in their strengths and ability to cope with stress. The fact that leprosy can be treated is emphasized to family members and patient alike. Stressing rehabilitation as an integral part of treatment beginning at diagnosis creates an encouraging atmosphere that can, in many instances, help counter initial depression and feelings of hopelessness.

Casework During Hospitalization

Following separation from his family, the new patient requires the support of the entire hospital team. The social worker is often one of the first staff members to see him. An understanding attitude and willingness to listen are the primary steps to harmonizing a troubled personality. The social worker establishes rapport with the patient by showing respect for him as an individual and interest in his particular concerns and problems. He also tries to muster the patient's resources and those of his family. A patient need not stand alone in his illness and the difficulties it causes. His religious faith may be of great help to him at this time.

While the practice is not as prevalent as it once was, there are still some patients who want to keep their names and whereabouts a secret. This makes recovery more difficult because the patient is left without the support of his family and friends. A 21-year-old, single Filipino girl was admitted directly from a west coast university, where she was a sophomore in the

college of education. At first she presented no problems, but was secretive and tended to keep to herself.

One day this patient asked to see the social worker, stating that she wanted to find some kind of employment in the hospital. Shortly, her real difficulty was revealed. No one among her family, her classmates, and her instructors was aware that she was hospitalized for treatment of leprosy. She felt that if she told them she would be promptly rejected, they would not understand, and she would not be able to return to college to finish her education. The patient had been born and grew up in the Philippine Islands where there are numerous cases of Hansen's disease. She knew about the adverse public reaction to those with this illness. Since she was on a student's visa, she feared deportation. Her distress was profound.

After many discussions of her situation, the social worker pointed out various courses of action she might take. She was finally able to disclose the nature of her illness to her parents. She received sympathetic support instead of the rejection she expected. Her mother came to the States to be with her. She then wrote to her classmates, who replied to her letters with understanding and encouragement. The worker discussed the patient's anxiety with an immigration officer and was assured that the patient would not be deported. The impact of all this on the patient was remarkable. Her fears and depression subsided, and she entered into the hospital activities wholeheartedly. She returned to school following discharge.

Depending on the new patient's ability to absorb information and his particular needs, an early orientation course on the disease is conducted. This may be done best by the physician or health educator. Actually other staff members, certainly the social worker, have a responsibility in orienting the newly admitted patient. Patients need to know the nature of their illness and what can be done for them as well as what cannot be done because knowledge shapes attitudes towards behavior. They need to know approximately how long hospitalization may be necessary in order to plan for their families and jobs.

During hospitalization patients bring many

well-known psychological mechanisms into play. Denial is readily seen in the refusal of some patients to accept the diagnosis of leprosy. To reject it completely is the mind's way of protecting itself from the harsh, painful reality of the situation. Depression, anxiety, or regression to a complete state of dependency can be observed in some, as hospitalization is extended and family ties become frayed or severed. Loss of interest in life is observed in some patients as are suicidal tendencies. But the suicide rate at Carville is no higher than that of the general population in the United States.

The social worker assists the patients in resolving marital and family difficulties. A patient's concern about family ties was demonstrated in the case of a 42-year-old, well-educated man admitted with a diagnosis of lepromatous leprosy. There was no noticeable disfigurement, and the physicians felt that his was "early disease." He was married, the father of two children, with an excellent job.

During the first months of hospitalization the patient became increasingly morose and depressed. This was particularly true after the first weekend visit by his wife. He had been given a pass to be with her away from the hospital. During an interview with the social worker the following week, it was revealed that the patient's wife was afraid of him—she feared "catching" his disease. The patient was greatly upset, said he felt "really contaminated," and became fearful himself that he might pass his disease to his wife. He muttered about "giving her her freedom now." His feelings, as well as his wife's attitude, were discussed. The worker pointed out that his wife's reaction and his own emotions were not unusual. The patient asked that the worker talk with his wife on the following weekend which was spent at the hospital.

The wife was found to be a mature, attractive, somewhat domineering person. During the interview she was nervous and restless, but talked eagerly about her fears regarding her husband's disease. She said it was wrong to feel that way but that she could not help it. She relaxed somewhat during a discussion of leprosy and the facts that are known about its transmission. The wife was able to recognize

the effect of her reaction on the children, her husband, their relationship, and his progress in the hospital. Later she was given a thorough physical examination by the physicians and found to be in excellent health. The possibility of her contracting the illness from her husband was interpreted as being quite remote. With such "talking out" sessions, the wife gained an understanding of her husband's disease and insight into his particular needs and how she could help him.

Placement of children born while the mothers are under treatment requires special planning. Various community agencies are called upon to help. For example, the local departments of public welfare are asked to arrange for foster care and supervision if no one in the patient's family can provide a home for the child. In certain cases State or church-supported child care institutions are asked to supply this service. The coordinated effort often involves cooperation with State, private, and voluntary organizations. The hospital social worker makes arrangements for the patient to visit her child periodically. These visits are very important to the mother because they relieve anxiety concerning her child and help her to accept the necessary separation. The child is kept in contact with his mother, who will eventually return home to assume his care.

Individual, patient-centered conferences are held weekly, and members of the professional staff involved in the patient's care and treatment participate. This team includes physicians, nurses, social worker, and chaplain, and the occupational, physical, and manual arts therapists who may be cooperating in his rehabilitation. The dietitian, the school principal, teachers, and special services and recreational supervisors may also attend. The patient's response to therapy is discussed as well as his progress, or lack of progress, in other areas. Changes in treatment or alterations of school or work programs may be recommended.

Each patient's case is reviewed at approximately 3-month intervals, but if a plan for his discharge is in process or some other need arises, discussions may be held weekly or monthly.

When one considers a few of the criteria for sound mental health (feelings of personal

worth, security, self-adequacy, and confidence) it is easy to see the need to follow patients closely and, hopefully, prevent a diminution of existing strengths when it is possible. Stress engendered by a hospital experience can be intolerable for some people and may be partly responsible for treatment failures. Treatment on an outpatient basis may be effective for some patients, and they may get along much better. Some find it extremely difficult to accept certain restrictions that are necessary in any hospital. Outpatient treatment can be provided by many Public Health Service hospitals or State health department clinics in various cities in the United States. The patient may report once or twice a week for his medications and monthly or bimonthly for bacteriological examinations and a thorough physical checkup.

Discharge and Followup

Discharge planning is important because patients frequently require more assistance at this point than at any other time. From the social worker's point of view, the patient's motivation is the most important factor in rehabilitation. Leaving the protective shelter of the hospital environment and returning to one's family or job can be frightening, especially if hospitalization has been for 5 or 10 years or there is residual disfigurement or disability.

Three important factors to consider in discharge planning are the patient's readiness to leave, his feelings about leaving, and his future plans. Group identification is comforting. Some patients require institutional protection and are psychologically unable to be discharged. They should not leave. The administration at Carville understands this problem and allows them to remain. On the other hand, it is recognized that custodial institutional care can contribute to the deterioration of some of the patients.

Discharge planning begins 3 to 6 months in advance of the date the patient will leave the hospital. The social worker plays a major role in these plans and also advises the medical staff when, in his opinion, a patient may be psychologically a poor prospect for discharge. For the patient who is ready to leave, the social worker contacts members of the family by telephone or letter or during visits at the hospital.

Some patients need help in finding a place to live and subsistence until employment is obtained. If the family is unable to provide this, the same government and volunteer agencies that assisted in pre-admission planning are again called upon for services. Participation of the family and community agencies is vital to facilitate the patient's acceptance in his former environment. Referral for vocational rehabilitation service or employment assistance may be needed if a patient is unable to return to the kind of work he did before hospitalization. Labor unions assist in training and locating job opportunities.

The cooperation of a former employer is illustrated by the case of a 33-year-old father of four children, who was ready for discharge after 4 years of treatment. The residuals of his disease included some minor facial scarring, partial loss of eyebrows, and a scar on his right arm at the site of an ulnar nerve transposition.

Before his illness, the patient had been employed for several years as a clothing salesman in a large establishment. At the time of hospital admission his employer had assured him that his job would be waiting for him when he returned. During the second discharge planning interview, the patient expressed doubts about returning to his old job. He felt that he might not be welcomed back and that his boss was just being nice in saying he wanted him back. He suggested that he might try to find other work where no one knew he had been sick and where he would not have to be in close contact with people, especially children.

Feelings of self-devaluation and lack of self-confidence permeated the patient's discussion of how he now saw his situation. His major strengths (his honesty, regard for others, and determination to return home and provide for his family) were mustered, and he agreed that the worker write to his former employer. A reply indicated that the employer had definite misgivings about the patient's return to work but was interested in helping him. He knew very little about leprosy. Succeeding letters explained the patient's disease and emphasized his abilities, work record, and needs.

The patient continued to resist returning to

the clothing department, so eventually a compromise agreement was made. A night maintenance worker had retired from the store, leaving his position open if the patient wanted it. The job would require some training, but he was eager for the opportunity. The social worker and the employer felt that the arrangement might be temporary, but it was the best that could be expected at that point. The opinion of both was that the patient really wanted to return to his job in the clothing department and would in time regain his self-confidence and be able to do so.

Casework was to be continued by the social worker who had helped in the planning with the patient's local health department.

Followup after discharge is an essential part of casework. Usually, when a patient is discharged, continued medication and periodic physical checkups are recommended by the physicians for long periods to prevent possible reactivation of the disease. When problems arise in the family and on the job, the services of the social worker are available to former patients who need help in resolving them.

Social acceptance with an awareness of the nature of the dischargée's disease is imperative if reintegration into the family and the life of the community is to be achieved. It has been demonstrated that to attempt to hide one's condition from a prospective employer is not advisable. If hidden, the possibility of being found out exists daily, and the pressure is too great for the former patient to contend with. Sharing the diagnosis with an employer is recommended, and this step affords a measure of job protection for the patient. There may be a problem relative to insurance liability in an employment situation because of the possibility of reactivation of a discharged patient's illness. In many cases this can be resolved satisfactorily.

The treatment and rehabilitation of the patient with leprosy demands a partnership—they are not solely Federal responsibilities. Our rehabilitation efforts have been most successful when State and local agencies have joined us in coordinated, integrated action. Final success is realized when the former patient is accepted in the community by his fellow men.

New Members Appointed To PHR Board of Editors

Three new members have joined the Board of Editors of *Public Health Reports*. Members of the board serve 3 years. Retiring from the board are Dr. Herbert R. Domke, Dr. Robert Dyar, Wesley E. Gilbertson, Charles V. Kidd, and Dr. James R. Shaw.

Bernard V. Dryer, M.D., a Cleveland physician, is active in education for medicine and the allied health sciences at local, national, and international levels. He was study director of the Joint Study in Continuing Medical Education sponsored by the American Medical Association, the Association of American Medical Colleges, the American Academy of General Practice, the American Psychiatric Association, the American Hospital Association, and various medical specialty boards. This study is summarized in his monograph, "Lifetime Learning for Physicians."

Dr. Dryer is a member of the Neurological and Sensory Disease Project Review Panel and a member of the Health Advisory Committee of the United Health Foundation. During the past year he has been planning consultant to the Association of American Medical Colleges, the University of Pittsburgh, and the School of Medicine of Hebrew University, Jerusalem. He is a member of the Committee on Medical Education of the American Heart Association and of the Committee on Health Education of the Cleveland Academy of Medicine.

Fremont Ellis Kelsey, Ph.D., is special assistant to the Surgeon General for science information, Public Health Service, with the duty of encouraging programs and practices in exchange of science information which are effective, responsive to needs, and consistent with methods favored by the Federal Council of Science and Technology and its Committee on Science Information.

Dr. Kelsey received his doctorate in 1939 from the University of Rochester (department of biochemistry and pharmacology). A 1935 graduate of the University of Pittsburgh, he returned there in 1939-40 as a National Research Council Fellow in the department of chemistry.

From 1940 to 1951, Dr. Kelsey was on the faculty of the department of pharmacology, University of Chicago. After a year as director of the radiochemistry department at Nuclear Chicago Corporation, he served



Dr. Dryer

Dr. Kelsey

Dr. Sox

as chairman of the department of physiology and pharmacology, School of Medicine, University of South Dakota, until 1960.

Dr. Kelsey next served in the Division of General Medical Sciences, National Institutes of Health, first as a program analyst in the Research Grants Branch and second as executive secretary of the special training grants program. He advised particularly on pre-clinical medical sciences, research with experimental programs in medical and research education, and on scientific communications and information retrieval.

Ellis D. Sox, M.D., is director of public health of the City and County of San Francisco.

From 1937, when he completed his internship at San Francisco General Hospital, until he assumed this directorship in 1952, Dr. Sox served in State and county public health posts in California. As a medical officer of the California State Department of Public Health, in 1937 he initiated the first mobile X-ray unit for diagnosing pulmonary tuberculosis among migratory agricultural workers. He was the first full-time health officer of Tulare County, Calif., filling this position from 1938 until 1941, when he became assistant chief, bureau of county health work, California State Department of Public Health.

Dr. Sox received his bachelor of arts degree from the University of Oregon in 1931, his doctor of medicine degree from the University's medical school in 1935, and his Certificate in Public Health from the University of California Curricula in Public Health (Berkeley) in 1938. He is certified by the American Board of Preventive Medicine and Public Health.

Active in a number of national, State, and local medical and public health organizations, Dr. Sox also serves as a consultant in preventive medicine and in epidemiology to local hospitals and as clinical professor of public health, University of California, School of Medicine. He writes a monthly column for the San Francisco Medical Society bulletin.